

# **South Dakota Children's Mental Health Task Force**

## **Final Report**

**South Dakota Department of Human Services**

**Division of Mental Health**

**Prepared by the WICHE Mental Health Program  
supported by an educational grant from  
Eli Lilly and Company**

**January 2003**

The Western Interstate Commission for Higher Education (WICHE) is a public interstate agency established to promote and facilitate resource sharing, collaboration, and cooperative planning among the western states for higher education and workforce needs. Member and affiliate states include Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, North Dakota, Oregon, South Dakota, Utah, Washington, and Wyoming.

This document was prepared by the WICHE Mental Health Program for the South Dakota Department of Human Services, Division of Mental Health, supported by an educational grant from Eli Lilly and Company.

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# **South Dakota Children's Mental Health Task Force**

## **Executive Summary**

The Legislature of the State of South Dakota passed legislation in 2002 establishing a Children's Mental Health Task Force. The purpose of the Task Force was to evaluate the current mental health care system for children in South Dakota and provide recommendations for system improvements to the Seventy-eighth Legislature. Staff of the Division of Mental Health convened the Task Force and utilized the Western Interstate Commission for Higher Education (WICHE) Mental Health Program to facilitate meetings and public comment, provide technical assistance, and obtain expert consultation. The Task Force generated seven recommendations providing direction to improve the mental health system in South Dakota.

The Task Force was comprised of 20 individuals representing family members, the State House of Representatives, the State Senate, advocacy organizations, ChM providers, non-CMHC providers, the Department of Human Services, four other State Departments, and the Unified Judicial System. The structure of Task Force meetings provided opportunities for public comment and discussion. Meetings also enabled the Task Force to hear presentations from experts in the field.

The Task Force report will be sent directly to the legislature. Additional reports will follow to inform the legislature of progress in implementing the recommendations. The Mental Health Planning and Coordination Advisory Council appointed by the Governor will be responsible for overseeing the implementation of the recommendations. It is comprised of representatives from other state agencies as well as family representatives. The Division of Mental Health will be the lead responsible agency.

The legislative action initiating the Children's Mental Health Task Force is indicative of an evolving understanding among public policy makers that the current system is falling short in its ability to effectively meet the needs of children with serious emotional problems and their families. Too often these problems lead to the collapse of the family's ability and capacity to care for their child. The call for a Task Force offered the State Department of Human Services the opportunity to increase community and consumer engagement. Implementing Task Force recommendations will significantly improve the system of care for families, children, and adolescents in South Dakota.

## **Task Force Recommendations**

Recommendations were generated at Task Force meetings facilitated by WICHE using a consensus-building method. Recommendations were based on public comment, responses to a survey, and input from experts in the field. Input included data on unmet need for services and presentations on: relinquishing custody; best practices for children and adolescents; and best practices for Native Americans. Chapter VII points to the basis for recommendations in this report. Minutes from meetings provide additional support for recommendations.

- 1. The Director of the Division of Mental Health shall work through the Mental Health Coordination and Planning Advisory Council to develop an action plan detailing options for parents/families of children with serious emotional disturbance (SED) to obtain public services without relinquishing child custody. This action plan shall be delivered to the Governor and Legislature by December 2003.**
- 2. Children and adolescents in the State of South Dakota shall be screened for social emotional development to promote early identification and intervention needs. This screening shall be integrated into existing services such as public health, school, and day care settings.**
- 3. The first step in seeking care is the knowledge regarding both the need for help and where to go for help. The Department of Human Services in cooperation with other public and private entities, shall initiate a public education campaign to increase public awareness of family, child and adolescent mental health issues and local resources for care.**
- 4. Interagency collaboration is essential to developing an effective system of care for children and families with mental health care needs. Interagency collaboration assures children and families progress to appropriate services on a continuum of care. Local areas need flexibility in building a system of care that works for their communities. State agencies shall coordinate to support the development of local systems of care through policies, regulations and funding mechanisms.**
- 5. The Legislature should explore means to enhance the availability of professionals trained to meet the mental health needs of children and adolescents, including statutory changes and training support of both new and existing professionals.**
- 6. Significant gaps in a continuum of services exist because of multiple factors. It is recommended that the Department of Human Services work with other State agencies to enhance funding for all services for children and families with behavioral health needs.**
- 7. The Department of Human Services and all mental health programs and staff throughout the state shall be knowledgeable and responsive to the diverse cultural backgrounds represented in the state. This recommendation is not separate but cuts across the implementation of all preceding recommendations.**

## **I. Introduction**

The Legislature of the State of South Dakota passed legislation in 2002 establishing a Children's Mental Health Task Force. The purpose of the Task Force was to evaluate the current mental health care system for children in South Dakota and provide recommendations for system improvements to the Seventy-eighth Legislature. Staff of the Division of Mental Health convened the Task Force and utilized the Western Interstate Commission for Higher Education (WICHE) Mental Health Program to facilitate meetings and public comment, provide technical assistance, and obtain expert consultation. The Task Force generated seven recommendations providing direction to improve the mental health system in South Dakota.

The Task Force was comprised of 20 individuals who met four times during the late summer and fall of 2002 in Pierre, Sioux Falls, and Rapid City. Task Force members represented family members (4 members), the State House of Representative (1), the State Senate (1), advocacy organizations (1), CMHC providers (2), non-CMHC providers (5), the Department of Human Services (2), four other State Departments (4), and the Unified Judicial System (1).

The structure of Task Force meetings provided opportunities for public comment and discussion. Scheduling of the meetings allowed for the public to interact with the Task Force both during and after normal "business hours." Testimony was received from family members, advocates, and representatives of organizations involved with children and families (e.g., schools). This testimony influenced Task Force recommendations and is documented in Task Force meeting minutes.

Meetings also enabled the Task Force to hear presentations from experts in the field. A special consultant discussed the issue of relinquishing custody to obtain mental health care for children. Relinquishment was an explicit concern of legislators in forming the Task Force and is a major issue in a number of states. Consultants were also brought in to present and discuss best practices in children's mental health, and Native American children's mental health initiatives. WICHE staff presented data on the number of children and adolescents in South Dakota with serious emotional disturbances, children served with public funds by Community Mental Health Centers, and an estimate of unmet need for public services in the State.

WICHE provided additional information on children and adolescent mental health to the Task Force in a three-ring binder. This included research and recent findings on serious emotional disturbance; cost and funding of services; transition to adult services; and information from the Surgeon General's report related to children and adolescents. In all, the Task Force had considerable information, outside comment from the public, and time for discussion.

The Task Force generated seven recommendations based on all of the input noted above and using the informed judgment of the members. These recommendations may be found in Chapter VIII of this document. Recommendations are preceded by an analysis of the following areas:

1. Gaps in the continuum of services;
2. Current service capacity;
3. Efficacy of early identification and intervention;
4. National best practices;
5. Alternatives to relinquishing custody to obtain out-of-home mental health services; and
6. Barriers to service delivery, such as professional shortages, funding adequacy, and access in rural areas.

This report will be sent directly to the legislature. Additional reports will follow to inform the legislature of progress in implementing the recommendations. The Mental Health Planning and Coordination Advisory Council appointed by the Governor will be responsible for overseeing the implementation of the recommendations. It is comprised of representatives from other state agencies as well as family representatives. The Division of Mental Health will be the lead responsible agency.

The legislative action initiating the Children's Mental Health Task Force is indicative of an evolving understanding among public policy makers that the current system is falling short in its ability to effectively meet the needs of children with serious emotional problems and their families. Too often these problems lead to the collapse of the family's ability and capacity to care for their child. The call for a Task Force offered the State Department of Human Services the opportunity to increase community and consumer engagement. Implementing Task Force recommendations will significantly improve the system of care for families, children, and adolescents in South Dakota.

## **II. South Dakota Resources for Children with Mental Health Needs**

### **The Department of Human Services**

As the State Mental Health Authority, the Division of Mental Health under the authority of the South Dakota Department of Human Services (DHS), serves as the central point of contact for State operated and funded mental health services for adults with SPMI (Severe and Persistent Mental Illness) and children with SED (Serious Emotional Disturbance). Established in 1989, the Department of Human Services structured services for individuals with disabilities under a consolidated leadership. Its mission is to "promote the highest level of independence for all individuals regardless of disability or disorder."

The Department includes the following Divisions: Alcohol and Drug Abuse; Developmental Disabilities; Mental Health; Rehabilitation Services; Service to the Blind and Visually Impaired; the South Dakota Developmental Center-Redfield; and the Human Services Center-Yankton.

### **The Division of Mental Health**

The Division provides a range of mental health services through purchase of service agreements with 11 non-profit Community Mental Health Centers. As mandated by state law, the principle responsibilities of the Division of Mental Health are to coordinate, plan, fund, and monitor a comprehensive community-based mental health delivery system.

The Division of Mental Health is responsible for: establishing policy; developing and administering the implementation of the Community Mental Health Services Block Grant and this State Plan under PL 102-321; determining and establishing reasonable standards and requirements for the locally operated Community Mental Health Centers; and entering into purchase of service agreements for the purposes of assisting the local mental health centers' operation and programs.

The Division of Mental Health has also assumed responsibility for the delivery of mental health services within the State's adult and juvenile correctional facilities. As a result of assuming the services within the correctional facilities, the Division was recently re-organized. The new organization includes a Division Director; a Program Manager for Community-Based Mental Health Services who oversees five Program Specialists; a Program Manager for Correctional Mental Health Services who oversees a contract Psychiatrist, two Psychologists and nine Mental Health Professionals for the adult correctional facilities; a Program Specialist and three mental health professionals for the juvenile correctional facilities; and one secretary.

### **The Human Services Center**

The Human Services Center is located in Yankton, in the southeastern tip of South Dakota. The Human Services Center is a state-of-the-art, licensed hospital, providing inpatient psychiatric treatment services, chemical dependency treatment services, and an assertive community

treatment program (ACT) called Individualized and Mobile Program of Assertive Community Treatment (IMPACT).

**Inpatient psychiatric treatment services:** Acute Psychiatric Services has a total bed capacity of 60. This area is Medicare approved by the Center for Medicare and Medicaid Services. Acute Psychiatric Services provides for initial assessment of patients and develops and initiates treatment and discharge plans. Acute Psychiatric Services, like all HSC treatment programs, promotes and facilitates independent functioning in daily activities, and provides care, treatment and rehabilitation services that will enable the patient to return to and function in the community at the earliest possible time. The following services are available to youth:

The Adolescent Acute Psychiatric Program provides adolescents, ages 13 through 17, with inpatient psychiatric evaluation and treatment. The goal of the program is to develop and initiate individualized treatment and discharge plans, provide effective treatment, and to support the patient in transition to home or another appropriate placement setting. This program contains 15 beds. Adolescents from this program attend an accredited Alternative School operated by HSC. An intermediate adolescent psychiatric unit is also available. This unit provides additional support and a slightly longer stay than the acute unit. This unit consists of 20 beds and serves adolescents ages 13 through 17.

The Long-Term Adolescent Treatment Program provides long-term psychiatric care for adolescents from 12 to 17 years of age. This program contains 12 beds. The goal of the program is to provide comprehensive diagnostic services in order to establish long-term treatment goals. The program works to promote and develop good communication skills and to help the adolescents achieve a better understanding of self, family, and peers. Goals are established to provide and enhance the educational, interpersonal, and basic living and socialization skills that will improve the chances for successful adaptation for movement into a less restrictive environment.

The Intensive Treatment Unit (ITU) is a secure psychiatric facility for certain HSC patients and forensic court evaluation treatment cases referred by circuit court. This unit provides a closer observation for patients who pose a high risk for harming themselves or others. ITU is a 14-bed unit that is structurally divided into two distinct areas. One area is designated for care of adolescents, the second area for care of adults.

The Adolescent Chemical Dependency Program is accredited by the Division of Alcohol and Drug Abuse as a 20-bed inpatient alcohol/drug treatment facility. Applicants must be 13-17 years of age and have a dependency diagnosis. The program is 60-120 days in length. Adolescents from this program attend an accredited Alternative School operated by HSC.

## **Community Mental Health Centers**

The third component of the State's mental health delivery network is composed of 11 private, non-profit community mental health centers. Each mental health center is governed by a local board of directors, and each center has a specific geographic service area for which it has responsibility. These centers must meet administrative rules promulgated by the State Division of Mental Health. The centers provide mental health services through purchase of service

agreements with the Division of Mental Health. Each center provides a comprehensive array of services to children with SED and adults with SPMI.

An array of services is provided across the age spectrum for persons with mental health needs, the priority populations for state supported mental health care are adults with severe and persistent mental illnesses (SPMI) and children with serious emotional disturbance (SED).

Specific to children is a continuum of services to meet the needs of youth and families with complex needs resulting from a child's serious emotional disturbance. These services are:

- in-home, school-based, and clinic-based individual therapy
- in-home family/education/support therapy
- case management
- assessment and evaluation
- psychological evaluation
- group therapy
- respite care
- emergency services
- intensive family services

### **Community Mental Health Provider Network**

**Behavior Management Systems (BMS)** in Rapid City serves the western third of South Dakota. The counties included in the BMS catchment area are Bennett, Butte, Custer, Fall River, Harding, Jackson, Lawrence, Meade, Pennington, and Shannon. BMS services include IMPACT - West, which is the Individualized and Mobile Program of Assertive Community Treatment.

**Capital Area Counseling Services, Inc. (CACS)** is located in Pierre and serves central South Dakota. The counties that CACS covers are Buffalo, Haakon, Hughes, Hyde, Jones, Lyman, Stanley, and Sully. In addition to providing community mental health services, the agency is a core service agency for providing alcohol and drug abuse services through the Division of Alcohol and Drug Abuse. CACS also operates a therapeutic foster care program.

**Community Counseling Services, Inc. (CCS)** is located in east central South Dakota in Huron and covers a six county area, including Beadle, Hand, Jerauld, Lake, Miner, and Moody. CCS serves as a core agency for providing alcohol and drug abuse services through the Division of Alcohol and Drug Abuse. CCS services include an IMPACT Program.

**Dakota Mental Health Center (DMHC)** in Mitchell serves a five county catchment area including Aurora, Brule, Davison, Hanson, and Sanborn counties.

**East Central Mental Health/Chemical Dependency Center, Inc. (ECMH/CD)** is located in Brookings, and serves Brookings County in east central South Dakota. ECMH/CD serves as a core agency for providing alcohol and drug abuse services through the Division of Alcohol and Drug Abuse.

**Human Service Agency (HSA)** in Watertown, in the east central part of South Dakota, serves a seven county area, including Clark, Codington, Deuel, Grant, Hamlin, Kingsbury, and Roberts. HSA is an umbrella organization providing professional services to children and adults with mental illness, developmental disabilities, and alcohol and substance abuse issues. HSA also operates Serenity Hills, a residential program that serves individuals with co-occurring mental health and chemical dependency issues.

**Lewis and Clark Behavioral Health Services (LCBHS)**, located in Yankton, in the extreme southeast portion of the State, provides services in seven counties, including Bon Homme, Charles Mix, Clay, Douglas, Hutchinson, Union, and Yankton. LCBHS serves as a core agency for providing alcohol and drug abuse services through the Division of Alcohol and Drug Abuse.

**Northeastern Mental Health Center (NEMHC)** in Aberdeen is located in the north central and northeast part of the State. It covers a large 10 county area, including Brown, Campbell, Day, Edmunds, Faulk, Marshall, McPherson, Potter, Spink, and Walworth counties. The center also operates a residential treatment program for children with behavioral problems and a therapeutic foster care program.

**Southeastern Behavioral HealthCare (SBHC)** is located in Sioux Falls, in the southeastern part of the State. Counties included in the SBHC service area are McCook, Minnehaha, Lincoln, and Turner. SBHC Children's Center also services children with developmental disabilities. SEBHC services include an IMPACT Program.

**Southern Plains Behavioral Health Services (SPBHS)** in Winner, is located in rural south central South Dakota. It covers the counties of Gregory, Melette, Todd, and Tripp. SPBHC serves as a core agency for providing alcohol and drug abuse services through the Division of Alcohol and Drug Abuse.

**Three Rivers Mental Health and Chemical Dependency Center (TRMHCCDC)** is located in Lemmon, in the northwestern corner of South Dakota. This agency provides services in four counties: Corson, Dewey, Perkins, and Ziebach. TRMHCCDC serves as a core agency for providing alcohol and drug abuse services through the Division of Alcohol and Drug Abuse.

All 11 community mental health centers belong to the Council of Mental Health Centers. This organization meets monthly and employs an executive director. The Council, through its committee structure, is involved in systems review and improvement efforts.

### **Mental Health Planning and Coordination Advisory Council**

Establishing an organized system of care requires a planning process that involves representation from consumers and families using the services, mental health service providers, and other related agencies and services.

The Council members are appointed by the Governor of South Dakota. The council meets quarterly, with all of the meetings being held in Pierre. The role of the Mental Health Planning and Coordination Advisory Council is defined in SDCL 27A-3-1.3-5. The Council serves to advise the Department of Human Services and the Division of Mental Health on the preparation of the state and federal mental health plans; on policy matters related to allocation of state and

federal funds, and on the coordination of planning and service delivery efforts. The Council also assists in evaluating services and continually works for needed program and service expansion. As they are completed, summaries of the accreditation surveys of CMHCs are presented to and reviewed by the Council. The Council can also play an important role in providing positive feedback to centers regarding areas of excellence as recognized through the accreditation process.

Beginning in May 1999, the Division reconvened the State Interagency Coordination Network Council (ICNC). It was discovered that the purpose of the ICNC, as well as the Local Interagency Teams (LITs), was not well defined. In addition there was a duplication of efforts between the ICNC and other State level interagency efforts. As a result of meetings of the ICNC, Advisory Council, and LITs, the Department of Human Services moved forward with repealing the State statutes related to the ICNC and LITs. ICNC membership has been incorporated into the Planning and Coordination Advisory Council's Children's Sub-Committee so that statewide issues regarding children's services can continue to be voiced to the Advisory Council. An interagency agreement was developed to endorse and encourage local interagency efforts.

### **Division of Alcohol and Drug Abuse**

The Division offers several levels of treatment in addition to specialized services. The Treatment levels were designed to allow placement of patients in the most appropriate level of care. The levels of treatment, while discrete, in reality represent points on a continuum of treatment services that could be used in a variety of ways depending on a patient's needs and response. Specialized services are provided to specific target populations.

Initial treatment level programs include: primary prevention; intensive prevention; early intervention; diversion (adolescent); and young adult alcohol diversion (19-20 year olds). (All programs are for adults and adolescents unless indicated otherwise.) Level II programs include: outpatient services; intensive outpatient services; and day treatment. Level III programs include: residential detoxification (adults); intensive inpatient services; low-intensity residential services (halfway house or transitional care); and continued care services. Specialized Services include: pregnant/parenting teen; pregnant women and women with dependent children; and gambling treatment services.

### **Department of Social Services**

The South Dakota Department of Social Services supports the care of children and families with mental health needs through two major systems: Medicaid and Child Welfare.

**Medicaid** - The South Dakota Medicaid Program is a federal/state partnership for the provision of health insurance benefits to low income families. The program is a major funding source for the provision of behavioral health services to children and families with mental health needs in South Dakota. Mental health and substance abuse coverage in Medicaid is "optional" under federal guidelines, and the South Dakota Medicaid Plan has chosen to cover services via two federal options: the Rehabilitation Option and the Clinic Option. The Rehab Option is the primary funding source for behavioral health services paid by Medicaid in the State's community mental health centers, while the Clinic Option is the primary Medicaid resource for private practitioners and hospitals.

**Child Welfare** - Resources are also made available through the State and the federal Title IV-E funding for children and families where child abuse and/or neglect has been identified. These resources provide for an array of services and support such as:

- foster care
- specialized treatment foster care
- group home care
- parenting training
- respite care
- emergency shelter
- residential treatment
- psychological and psychiatric evaluation
- family and individual counseling

### **Public and Private Schools**

Support for children and families with mental health needs is available through South Dakota Schools through Special Education Services and School Counselors. Special education services for children with identified serious emotional needs are delivered via an Individualized Educational Assistance Plan (IEP), which is developed in partnership between the school, parent, and child. Funding for these services is provided through a combination of federal and state resources. Special education services are available to both public and private schools.

While many schools have school counselors, the degree to which these counselors are prepared or capable of providing behavioral health interventions is unknown. Furthermore, individual clinical services are not within the scope of practice for school counselor certification. Many of the Community Mental Health Centers, under contract to the State, provide mental health services to children on-site at local schools.

### **Indian Health Service**

The Indian Health Service (IHS) is a branch of the U. S. Public Health Service, which is responsible for the health care of Native Americans as an entitlement established by various treaties between the United States of America and the nation's indigenous peoples. The IHS, either directly or via contract providers, operates hospital and clinic services for the Native American people on each of the Native American Reservations in South Dakota, and an off-reservation center in Rapid City. Mental health services for children are available through the IHS and its contract providers, and through various other tribal Social Services programs. These services for Native American youth are limited, and many tribal youth are served in non-IHS programs within the public mental health system in South Dakota.

### **Private Mental Health Services**

Many mental health providers are organized in independent private practice, and data on exact numbers and locations are not readily available. From the data that are available, and through testimony provided to the task force, it is clear that most independent providers of mental health services are located in the State's larger communities. Specialists such as child psychiatrists and

child psychologists seem to practice exclusively in the larger communities of Sioux Falls and Rapid City (with the exception of the Human Service Center in Yankton).

#### Military **Health** Systems

The U.S. Air Force operates health facilities for its personnel and their dependents at Ellsworth Air Force Base in Rapid City. Mental health services for dependent children of military personnel are available directly through the health facilities at the base and via private providers. Mental health outpatient services also are provided through the Veterans Administration facility at Fort Meade.

### III. Assessment of Need and Utilization of Public Mental Health Services for Children

This chapter is based on a project that was designed to assess the prevalence of serious emotional disorders and count the number of children and adolescents receiving services.<sup>1</sup> Newly developed technology was used to estimate the number of individuals in the population with serious disorders (*prevalence*). Prevalence estimates of children with serious emotional disturbances were limited to children in households below 300% poverty, to focus on those with a need for publicly funded services. The project also calculated the number of individuals who received services from CMHCs contracting with the Division in the same year (*utilization*). Utilization figures include all individuals serviced by CMHCs with State contracts or Medicaid funds. The difference between *prevalence* and *utilization* produced estimates of unmet need in the public sector.

Below is a list of major findings in this project. This is followed by a more detailed description of methodology and data.

#### Major Findings

- Of 12,035 children and adolescents (below 300% poverty) estimated to have a serious emotional disturbance (SED), 5,010 (42%) were served by CMHCs funded through State contract or Medicaid in CY2001.
- The remaining 7,025 youths (58%) with SED who were not served represent unmet need in the public sector.
- Adolescents (age 12-17) had the highest percentage of service (72%), while children from 0-5 and 6-11 had penetration rates of 11 % and 41 %, respectively.

<sup>1</sup> The project was funded through a SAMHSA/CMHS Data Infrastructure Grant to the Division of Mental Health.

## Methodology and Data

The population of interest was children and youths (under age 18) who could qualify for public funding of services. Services are provided under a sliding fee scale. Children and adolescents in family households with incomes under 300% of federal poverty guidelines were included in prevalence estimates.

Prevalence estimates were generated of children and adolescents with serious emotional disturbance (SED) in accordance with federal definitions. Considerably more research was available on the prevalence of SED for adolescents than children. Estimates for children were calculated using the same rates found for adolescents.

Rates found in research were applied to county and demographic groups using 2000 Census population data to the extent available. The summary table below shows that approximately 12,155 children and adolescents in households below 300% poverty in South Dakota had a serious emotional disturbance in the year 2000 (the same figure was used for 2001). (The 12,155 figure differs from the statewide 12,035 reported on the previous page. The difference is less than 1 % and may be ignored. The cause is in the estimation method: one figure is a statewide estimate and the other is an estimate by service area aggregated. A similar problem occurs in counts of clients served: an unduplicated count statewide is smaller than an unduplicated count by service area aggregated.)

South Dakota Children and Adolescents				
Ages	Population in Households (HH)	HH Pop. Under 300% Poverty	% SED	Persons SED
00-05	61,316	47,457	8.35%	3,961
06-11	67,274	50,961	8.22%	4,191
12-17	71,716	49,097	8.15%	4,004
Under Age 18	200,307	147,514	8.24%	12,155

The number of individuals served directly by the mental health system was calculated from the Division database of CMHC services. Counts were generated for each CMHC and aggregated. The table on the following page shows 5,010 individuals served by the mental health sector in CY2001.

A measure of unmet need was obtained by subtracting the number served from prevalence estimates of individuals with serious emotional disabilities (SED) below 300% poverty. Approximately 7,025 children and adolescents were identified in need of services that did not receive them. This was 58% of the individuals estimated to have a serious emotional disturbance.

## Prevalence Estimates and Individuals Served

(Used to Estimate Unmet Need and Penetration Rates)

CMHC	Individuals with SED (Households Under 300% Poverty)				Individuals Served by CMHCs 2001 CY			
	Age Groups				Age Groups			
	0 - 5	6-11	12-17	Total	0 - 5	6-11	12-17	Total
BM	995	1,058	991	3,044	143	346	622	1,111
02.CAC	192	203	197	592	15	83	125	223
03.CCS	176	230	249	655	31	134	220	385
04.DMH	171	193	204	568	17	137	402	556
05.ECM	113	120	114	347	20	68	105	193
06.HSA	317	368	385	1,070	33	143	267	443
07.LCB	401	430	421	1,252	18	182	261	461
08.NMH	335	380	390	1,105	51	145	335	531
09.TRM	145	161	153	459	69	319	345	733
10.SBH 1	863	779	717	2,359	13	81	140	234
1.SPB	196	203	185	584	10	65	65	140
Total	3,904	4,125	4,006	12,035	420	1,703	2,887	5,010

Unmet Need			
Age Groups			
00-05	06-11	12-17	Total
3,484	2,422	1,119	7,025

Penetration Rate (% Served)			
Age Groups			
00-05	06-11	12-17	Total
11%	41%	72%	42%

(Unmet Need was derived by subtracting the number served from the prevalence estimate. Penetration Rate was calculated with the number served in the numerator and the prevalence estimate in the denominator.)

Estimates of unmet need were conservative (low) for three reasons and high for another reason. They were low because: 1) prevalence estimates were limited to the population of persons with SED and did not include others (e.g., with acute needs for crisis services); 2) utilization counts included all individuals served, even if the individual was not identified with a SED; and 3) people were counted if they received only one service (even an assessment).

Estimates of unmet need were high because mental health services may be provided for people who cannot afford them through providers other than CMHCs. This was judged to be small relative to the number served by CMHCs. One source would be Medicaid-funded services through providers other than CMHCs; a plan is in place to incorporate these counts. Another potential provider or purchaser of mental health services is schools; however, there do not appear to be many children receiving mental health services from schools. Another source would be non-CMHC providers offering pro bono services.

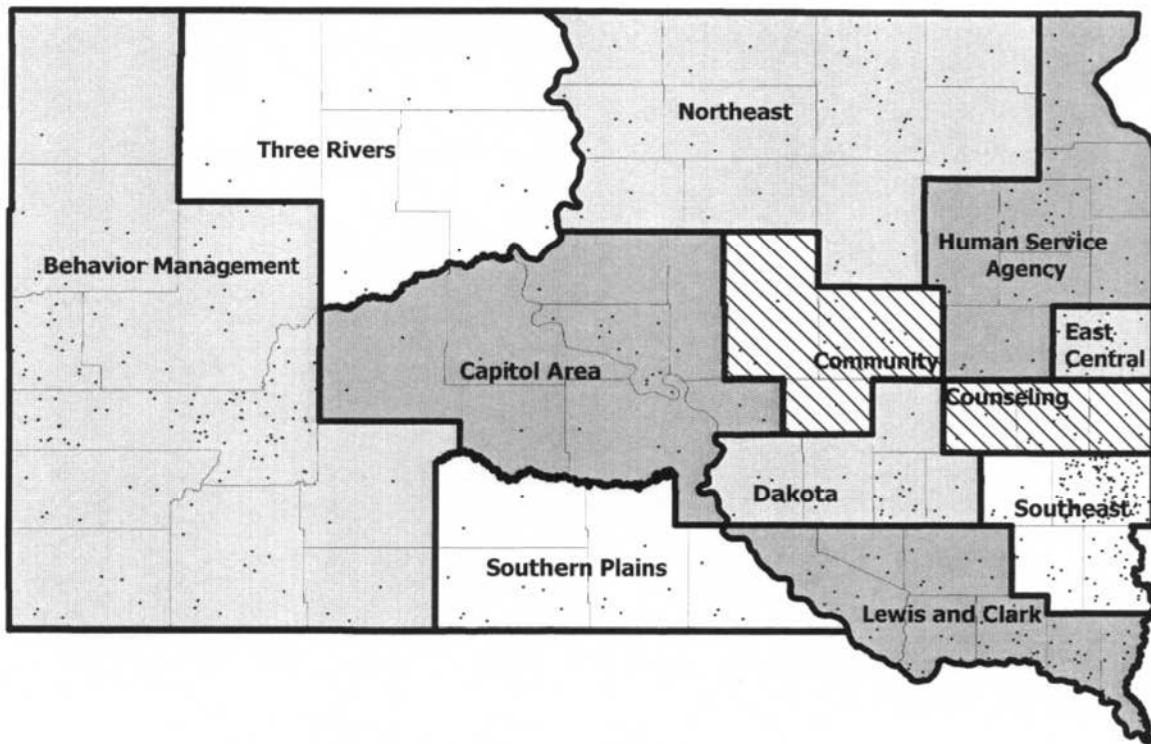
## **Use of Findings**

Findings should be validated with other information sources to the extent possible. Then it would be useful to discuss findings with stakeholders to understand the limitations. Consider, for example, service utilization data: a count of individuals served relates to only a part of the capability of the system, it does not address the appropriateness or amount of services provided. Finally, information may be integrated with other knowledge gained by stakeholders to inform decision-making. Findings may be used for:

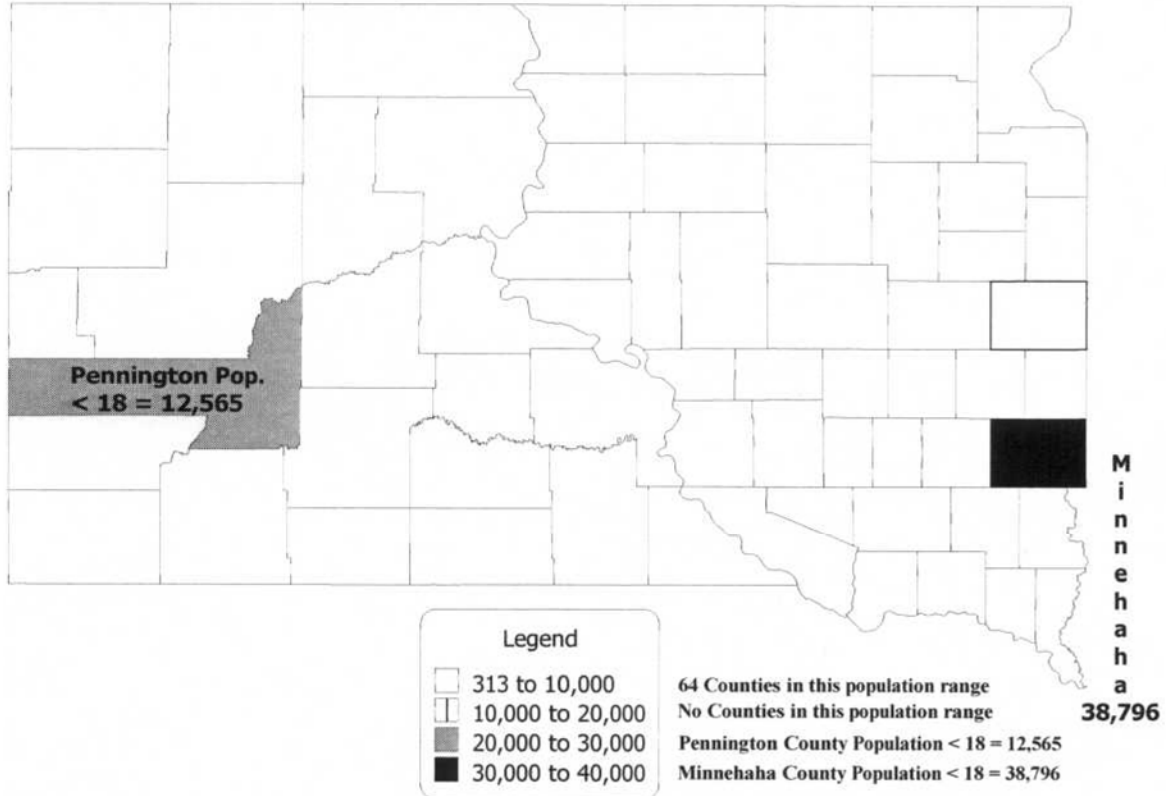
- Policy discussion. Was the population of interest defined and identified appropriately? (Is the 300% of poverty cutoff adequate to include individuals with serious disorders who are uninsured or underinsured for mental health?)
- Advocacy for families, children and adolescents not served.
- Mental health planning. Findings may help target needed services by geographic area and age group. Penetration rates may be used as a performance indicator of access to services. Indicators may be generated for gender or race/ethnicity differences.

Attached maps show mental health service areas and the density of the population of children and adolescents in each county. Two counties sum to 30% of the State population of children and adolescents: Minnehaha with 38,769 individuals, and Pennington with 12,565. (The next highest count was Brown County, with 8,375 individuals.)

# 2000 County Population Density Children and Adolescents



## South Dakota Children and Adolescents 2000 Population Groupings Map



## **IV. Children's Mental Health Systems of Care and Best Practices**

To be effective, systems of care (SOC) require foundational principles that organize and direct the activities of each component of the system. The principles should also guide individuals' actions and be consistent with the shared interests of children and adolescents, their families, and providers. Below is a list of 11 principles that have been identified as composing an ideological foundation upon which a SOC for child and adolescent mental health services can be built.

1. Access to a comprehensive array of services that address their physical, emotional, social, and educational needs.
2. Individualized services in accordance with each child's/family's unique needs/potentials.
3. Services in least restrictive, most normative environment.
4. Families as full participants.
5. Integrated services with linkages among child-serving agencies for planning, developing, and coordinating services.
6. Case management to ensure coordination of services with changing needs.
7. Early identification and intervention to enhance the likelihood of positive outcomes.
8. Ensure smooth transition to adult services as they reach maturity.
9. Rights of children should be protected and advocacy should be promoted.
10. System of care should be culturally competent.
11. System of care should be community based.

The principles listed serve primarily as guidelines, the realization of which is left up to those who are implementing a system. Different communities have different needs, as do different children or adolescents and their families. For example, whereas one community may need more day treatment programs, another may need more family therapists. Thus, the principles place value on individualized and context-relevant decisions regarding that which a particular system will focus on.

### **Key Components in a System of Care**

As indicated above, the principles on which a system is based help to guide the components of the system. The components of a system range from the individuals and their families receiving services, to care providers, administrators of facilities, community and state groups or associations, and local or state governments. The responsibilities and capabilities of persons in each component may differ, but a solid system of care helps to ensure that the interests of all parties remain the same and are achieved. The following section will discuss five areas that bear on the activities of multiple components of a system of care: wraparound, evidence-based services, family involvement, evaluating the system of care, and financing the system of care.

## **1. Wraparound**

### **Elements of Wraparound**

The Wraparound approach to SOC has several core elements: 1) a strength-based approach; 2) family involvement in the treatment process; 3) needs-based service planning and delivery; 4) individualized service plans; and 5) an outcome-focused approach. Each of these elements serves to establish more effective, long-term structures of help and treatment within a given youth's own family and community, thereby leading to better functioning for the youth.

- a) Strength-based approach: evaluates a family's strengths and culture with an eye toward natural supports in the family, neighborhood, or community.
- b) Family involvement: families should be viewed as capable and knowledgeable about their children's needs and as the primary source of facilitating treatment.
- c) Needs-based services: the family is an active partner, whose assessment of their children's needs should be listened to and taken as a guide for treatment.
- d) Individualized service plans: a youth's needs can span from medical to psychological to educational, and an individualized service plan properly assesses the needs of a given youth.
- e) Outcome-focused approach: requires clear goals determined through collaboration among the youth, family, and professionals that are continually measured and evaluated.

### **Importance of Wraparound**

Common sense indicates that youths are best served in their home communities with the active participation of family, have access to a wide array of integrated services, and are viewed from a strength-based perspective. A growing body of research tends to support this.

There have been a number of well-known initiatives to create wraparound services, as well as concomitant research to evaluate outcomes. As a whole, research indicates effectiveness in achieving important system improvements, such as reducing use of residential and out-of-state placements. Additionally, findings report increased parental satisfaction in systems of care than in more traditional service delivery systems.

Unfortunately, there have not been uniformly positive results in all areas. For instance, data regarding the effect of SOC on cost is not yet clear, nor has it been consistently demonstrated that services within a SOC will result in better clinical outcomes than services delivered within more traditional systems. Ongoing research will undoubtedly focus on what may or may not be happening with regard to cost and clinical outcomes, which will facilitate changes to SOC's within these domains.

## 2. Evidence-Based Services

### Array of Effective Services

Below is a list of services judged to be effective in helping children or adolescents and their families deal with psychological problems. As can be seen, the list indicates just how wide-ranging the potential treatment options can be, which is consistent with the principle of integrated, accessible, and comprehensive services to youths.

Array of Effective Services	
Prevention	Case Management
Assessment	Day Treatment
Mobile Crisis	Independent Living
Other Emergency Services	Therapeutic Foster Care
Outpatient Treatment	Therapeutic Camp
Home-Based Therapy	Treatment Group Home
Family Support	Residential Treatment
Mentoring	Crisis Residential
Respite Care	Inpatient Hospitalization

### Best Practices

Best practices may be defined differently by different people, but generally refer to those treatment interventions that are considered most effective on the basis of outcome research and/or community standards. It is always preferable to have solid research that documents the effectiveness of a given practice, but research is costly and time-consuming. Treatment cannot always wait for research, which means that clinicians must implement interventions that have shown positive results for them and their colleagues. Fortunately, several best practices in working with children and adolescents have both supporting research and anecdotal support from practitioners. These are prevention, Multidimensional Treatment Foster Care, and Multisystemic Therapy.

### Prevention and Early Intervention

Stopping problems before they start is not only common sense, it is common practice. Expectant mothers learn about healthy pre-natal practices and/or the elimination of potentially harmful behaviors (e.g., smoking and substance abuse). Infants are immunized against harmful diseases, and immunizations occur at different points in life. In a similar sense, prevention efforts regarding mental health for children in high risk environments is designed to have similar results. Prevention means less money spent on treatment later. However, more importantly, prevention reduces unnecessary and unneeded suffering.

Even in circumstances where youths have already begun having problems with the law, substance abuse, or other behavior problems, research has indicated that early intervention produced favorable results. For instance, the results of an early home visitation program reduced arrests, substance use, elopement from the home, behavior problems, and sexual behavior with multiple partners.

Additionally, parenting skills training reduced antisocial behavior in children, and programs such as Head Start facilitated better peer relations, less truancy, and less antisocial behavior. Early intervention programs in child care settings have improved intellectual development and academic achievement. Early screening programs in elementary schools improved academic achievement and adjustment. Finally, targeted prevention efforts have shown reductions in suicide, alcohol and drug abuse, teenage pregnancy, and juvenile delinquency.

### **Early Childhood System of Care**

Data indicate that young children (ages 1-6) receive a very low percentage of mental health treatment compared to older children and adolescents, despite an apparent need for such services. An early childhood system of care may be a useful way to address service deficits for these children. Such a system seeks to achieve several goals, including: 1) promoting emotional wellbeing of infants and young children; 2) providing assistance to families; 3) expanding competencies of caregivers; 4) ensuring young children with early symptoms have access to services; and 5) involving multiple community resources (e.g., Head Start, schools, and health care).

### **Multidimensional Treatment Foster Care (MTFC)**

Elements: Multidimensional Treatment Foster Care has several important elements. It is designed as an alternative for residential treatment or incarceration for youth with serious emotional disturbance (SED) or seriously violent, antisocial, substance-abusing behavior. Such programs emphasize low child to caretaker ratios, with one to two children per foster home. The program also involves intensive training and supervision, and an outcome-focused approach that utilizes daily behavioral measures. Treatment lasts approximately six to nine months.

The goals of treatment are as follows:

1. Encourage normative and pro-social behaviors.
2. Provide close supervision.
3. Specific, clear, and consistent limits and follow through on rule violations with nonviolent consequences.
4. Encourage academic skill development.
5. Teach new skills for forming relationships with positive peers and for bonding with adult mentors and role models.
6. Limit access to negative/delinquent peers.
7. Support biological family members to increase the effectiveness of their parenting skills.
8. Decrease conflict among biological family members.

MTFC has clear expectations for each participant in the treatment process. These are outlined as "core components" for the youth, treatment foster care (TFC) parents, and the biological parents and family of the youth. Below is a table of these core components for each participant.

<b>Multidimensional Treatment Foster Care</b>		
<b>Core Components for Youth</b>	<b>Core Components for TFC Parents</b>	<b>Core Program Components for Families</b>
Daily structure and support via a point and level system.	Conducts daily behavior management point and level system.	Weekly family counseling focusing on Parent Management Training.
Daily school card.	Daily telephone contact (M-F) and data collection.	Instruction in behavior management methods.
Weekly skill building and advocacy.	Weekly support and training meetings.	Home visits with crisis back-up.
Close supervision of location and associations.	24-hour, 7-day on-call case manager.	24-hour, 7-day on-call to case manager.
Recreational skill building.	Emergency crisis intervention.	Aftercare parent group.
Weekly contact w/ parents and frequent home visits.	Respite.	
Psychiatric consultation.	20 hours of pre service training.	
Daily mentoring by TFC parents.		

Research on the effectiveness of MTFC indicates the following results:

- Lower re-offending rates, higher rates of successful reunification with families for youth served through MTFC than youth served in group care (Chamberlain & Reid, 1998);
- Greater program completion rates, fewer runaways, lower incarceration rates than group homes (Chamberlain & Moore, 1998); and
- Fewer disruptions in placement and lower rates of problem behaviors than traditional foster care (Chamberlain, Moreland, & Reid, 1992).
- There has also been external replication.

Multisystemic Therapy is a community-based, family-driven treatment for youths with antisocial/delinquent behavior. Its focus is on "empowering" caregivers (parents) to solve current and future problems. Thus, the MST "client" is the entire ecology of the youth: family, peers, school, and neighborhood. So far, MST is being used in more than 30 states in the U.S. Additionally, it is a state-wide program in Connecticut, Colorado, Hawaii, Ohio, and Nebraska. It is a nation-wide program in Norway (25+ teams covering 17 of 19 counties), and has been replicated in Canada, Ireland, England, Sweden, and New Zealand.

A table of specific features of the MST program is provided below. These include identification of the treatment provider, length of treatment, the nature of treatment, and so forth.

<b>Multisystemic Therapy - Home-Based Services</b>	
<b>Treatment Site</b>	In the field: home, school, neighborhood, and community.
<b>Provider</b>	Single therapist (as part of.. and supported by, a generalist team).
<b>Treatment</b>	Total behavioral health care.
<b>Case Management Function</b>	Service provider rather than broker of services.
<b>Treatment Duration</b>	3 to 5 months in most cases.
<b>Clinical Staff\Client Families</b>	1: 4-6 (average is 15 families\yr\therapist).
<b>Staff Availability</b>	24 hr\7 day\work team available.
<b>Treatment Outcomes</b>	Responsibility of staff and agency.
<b>Expectations of Outcomes</b>	Immediate, maximum effort by family and staff to attain goals.

Research on the effectiveness of MST includes a number of experimental clinical trials and the use of an "MST Therapist adherence measure," a 26-item questionnaire completed by the youth's parents or caregiver. Data from the clinical trials indicates:

- Reduction in re-arrest rates by 25% - 75%.
- Reduction in out-of-home placement 47% - 64%.
- Improved family relations/functioning.
- Reduction in drug use.
- Reduction in aggression.

Data from the MST Therapist adherence measure predicted:

- Decreased criminal activity.
- Decreased incarceration.
- Decreased adolescent emotional distress.
- Increased parental emotional distress.

Studies of MST indicate a total cost of \$4,500 to \$8,500 per family served, which is driven by staff salaries. Additionally, \$300,000 is a typical minimum to implement an MST program to serve 40 - 50 families per year.

### **3. Family Involvement**

Preceding sections have documented the crucial role families are viewed as playing in the entire treatment process. From assessment to therapy and advocacy to outreach, families, especially parents, are held to be the core value that youths possess. This viewpoint does not ignore or diminish the role family dysfunction and abuse may play in the development of emotional disturbance in children and adolescents. However, it is not clear that a focus on the negative aspects of a given family is more successful in bringing about positive changes. Thus, the programs discussed have sought to identify sources of strength within and around families that can facilitate improvement in problem areas. Time and further research will help clarify these important issues.

In the meantime, lessons have already been learned with regard to the interface between family systems and mental health care systems. These lessons include:

1. Wraparound can be useful in maximizing family involvement in service delivery.
2. Assessing family's perspective of involvement.
3. Families need to choose their own leadership.
4. Balance between local family support needs and statewide involvement.
5. Family involvement is critical for systems change.
6. Involve families in defining functions of a family organization.
7. Clearly specify requirements.
8. Family organizations need assistance.
9. Youth input is important, too.

A broader issue is that of cultural competence. Families have their own particular culture and also live in the context of a wider community, state, and national culture. For mental health service providers, key questions include: do families feel like their culture is respected and does the service array include appropriate services for particular cultures (e.g., native healers)? Of course, these are not the only questions that become relevant in this regard, and cultural competence is concerned with issues of race/ethnicity, socioeconomic status, rural vs. urban, religion, gender, sexual orientation, and so forth.

Mental health organizations also need to be aware of potential biases built into their systems. Such biases can be manifested in training, relative number and quality of

services related to the general population, the presence or absence of bilingual staff and/or interpreters, the culture of the staff itself, and the administrative structure.

#### **4. Evaluating the System of Care**

As indicated in the previous and earlier sections, evaluating a system of care is crucial and should be built into the system as an ongoing endeavor. A system of care evaluation is designed to answer the following critical questions:

- Who are we serving?
- What services are they receiving?
- Are services delivered in accordance with the service delivery model?
- What is the cost of service delivery?
- What are the outcomes produced by services?

There are also more complex questions that an evaluation must answer, such as:

- Are we serving the right children/families?
- Does adherence to a model affect outcomes?
- Which services are most effective for which types of children?
- How are costs associated with service trajectory?

Valuable lessons are learned continually that help in answering the above questions in a manner that is useful to various interested parties. Among these lessons are:

1. Data are critical in sustaining and expanding the system of care.
2. Data need to be useful to practitioners.
3. Evaluation needs to be owned by the system of care.
4. Families are important in evaluation design, data collection, and interpretation of results.

#### **5. Funding the System of Care**

As one might expect, one of the ongoing, major challenges of successfully developing, implementing, evaluating, and improving a system of care is funding. One must have in place a sound funding strategy that is efficiently directed toward the essential aspects of the system (e.g., treatment, evaluation). Financing should be driven by the system of care vision, which in turn is based on the needs of children and families. Funding should be flexible, integrated, braided, or coordinated

To be successful, financing strategies require a clear, articulate, shared vision that enjoys broad-based support. With this comes the need for sound knowledge of funding requirements for a given system. In this regard, having solid data that document the strengths and weaknesses of a given system is essential. However, despite the importance of good data, family involvement in both therapy and advocacy initiatives goes a long way toward helping policymakers see more clearly and directly the importance of mental health services. Additionally, marketing strategies that effectively

educate consumers or potential consumers about the availability and range of services are also helpful. Crises, be they for an individual, family, or community, are times when people will seek help and a sense of stability - a role that mental health service providers are trained to adopt. Nevertheless, funding a system of care is a long-term commitment that must not be forgotten or minimized.

## **Funding Options**

During the development of a system of care and a funding strategy, decision makers will have to assess the types of funding available to determine how best to access or allocate money to the system and its components. For example, a system could try to access new funding through new state appropriations and federal or foundation grants. Title IV-E Waivers might be used for room and board for eligible children in out-of-home placements; the waiver also allows funds to be used for innovative services to prevent out-of-home placement. Additionally, systems could use existing funds (e.g., mental health, child welfare, education) differently. Systems of care can also look for matching opportunities. Of course, Medicaid funding has been and will likely continue to be a major source of funding for children's mental health services. Below are some options related to Medicaid, as well as some of their qualities.

### **1. Home and Community Based Waiver**

- Can expand eligibility.
- For children who meet hospitalization criteria.
- Cost neutrality.
- Can limit capacity.
- Can limit geographically.
- Can add innovative services.

### **2. Tax Equity and Fiscal Responsibility Act (TEFRA) (Katie Becket Option)**

- Can expand Medicaid eligibility.
- Allows children eligible for medical institutions to be cared for in the home.
- Cost neutrality.
- Allows child access to all Medicaid benefits.
- Cannot limit capacity or geographically.

### **3. Health Insurance Flexibility and Accountability (HIFA)**

- A newly developed Medicaid and State Children's Health Insurance Program (SCHIP) section 1115 waiver approach.
- The primary goal is to encourage new comprehensive state approaches that will increase the number of individuals with health insurance coverage within current-level Medicaid and SCHIP resources.
- A particular emphasis on broad statewide approaches that maximize private health insurance coverage options and target Medicaid and SCHIP resources to populations with income below 200% of the Federal poverty level (FPL).
- Encourage innovation to improve how Medicaid and SCHIP funds are used to increase health insurance coverage for low-income individuals.

- Give States the programmatic flexibility required to support approaches that increase private health insurance coverage options.
- Simplify the waiver application process by providing clear guidance and data templates.
- Increase accountability in the State and federal partnership by ensuring that Medicaid and SCHIP funds are effectively being used to increase health insurance coverage, including substantially more private health insurance coverage options.
- Give priority review to State proposals that meet the general guidelines of the HIFA demonstration project outlined below.

For more information, see <http://www.cms.hhs.gov/hifa/default.asp>

## V. Relinquishing Custody to Obtain Services

The practice of requiring parents to relinquish custody in order to obtain essential mental health services and supports for their children has been addressed by The Nation's Voice on Mental Illness (NAMI), the Bazelon Center for Mental Health Law, and the Federation of Families for Children's Mental Health (FFCMH). In separate papers, all three have appropriately condemned this harsh reality as either "heinous," "unspeakable," or "unthinkable." The FFCMH states:

These public practices:

- lead children to believe they have been abandoned by their family into the care of the state thus irreparably harming the bond between the child and family;
- force parents to make an otherwise unthinkable choice between retaining responsibility for and a relationship with their children and giving over decision making authority and control to a state agency in order to obtain the help their child desperately needs;
- waste public funds by keeping children as wards of the state when their basic needs could otherwise be provided by families who love them; and
- force children into expensive residential placements rather than supporting families and promoting the development of less costly community-based services.

The papers also discuss relevant background issues, court cases, and offer recommendations for how to resolve this difficult issue.

In July 1999, NAMI printed the results of their national survey of parents and other caregivers, titled *Families on the Brink: The Impact of Ignoring Children with Serious Mental Illness*. They reported that 23% of the respondents reported having been told that they would have to relinquish custody of their children to get services, and 27% of those so told did give up custody for that purpose (p. 10).

The "Executive Summary" portion of the Bazelon (2000) report, *Relinquishing Custody: The Tragic Result of Failure to Meet Children's Mental Health Needs*, indicates that although "state child welfare agencies do not distinguish between children who are subject to abuse and neglect and those placed only for access to mental health services ... several surveys of parents and state agencies indicate that the problem is pervasive" (p. 3). The report further indicates that relinquishment of custody appears to be a problem in at least half the states, including those in which policies and statutes against relinquishment are in place. (See also <http://www.bazelon.org/issues/children/publications/index.htm>.)

## **Background and Contributing Factors**

Both the FFCMH and Darcy E. Gruttadaro, NAMI Senior Attorney, authored separate synopses of the Bazelon report that describe the issues and factors relevant to relinquishing custody. The FFCMH writes:

Parents who are responsibly trying to raise children who have mental, emotional, or behavioral disorders search for appropriate and effective treatments, services, and supports to help their child. Sometimes, this search forces parents who have exhausted their own financial resources, including health insurance benefits, and are not eligible for Medicaid, to transfer custody of their children to state authorities in order to access public funds to pay for necessary mental health care, services and supports.

[http://www.ffcmh.org/New%20Site/factsheet custody.htm](http://www.ffcmh.org/New%20Site/factsheet%20custody.htm)

The FFCMH paper documents some of the factors contributing to the practice of relinquishment of custody, which are provided in the list below.

1. Inadequate funding of mental health services and support for children and their families.
2. Lack of incentives to develop effective community-based systems of care to help families keep their children with emotional, behavioral, or mental disorders at home, in school, safe, and out of trouble.
3. Insufficient mental health benefits in private and public insurance plans cause families to exhaust benefits before the mental health needs of their child are fully addressed (especially when the child's condition is chronic and intensive intervention is periodically required).
4. In the absence of federal law that would entitle children to services for their mental illness and no single source of state or federal funding, families must attempt to access services from several uncoordinated and poorly implemented entitlement programs.
5. Private health insurance is often not an option for families with a seriously mentally ill child because policies place severe restrictions on benefits for the treatment of mental illnesses.
6. Medicaid, the Individuals with Disabilities Education Act (IDEA) and other programs designed to provide and/or finance services for children with serious mental illnesses have also fallen short, with the result that parents and caregivers may be forced to enter the juvenile justice or child welfare system just to access critically needed services.

## **Why Systems Fail Families**

Gruttadaro reports the findings of the Bazelon report regarding the reasons why current systems have failed families seeking services for mentally ill children and adolescents. She focuses primarily on Medicaid, the Individuals with Disabilities Education Act (IDEA), and the Child Welfare System. (For legal challenges and other documentation related to relevant court cases, see the report at <http://www.nami.org/youth/custody.html>.)

## **Medicaid**

The Federal Medicaid law for Medicaid eligible children requires Early, Periodic Screening, Diagnosis and Treatment (EPSDT). The federal Medicaid law provides that eligible children are entitled to EPSDT, which consists of two mutually supportive, operational components:

- (1) assuring the availability and accessibility of required health care resources; and
- (2) helping Medicaid recipients and their parents or guardians effectively use these resources.

States are required to provide necessary health care, diagnostic services, treatment, and other measures to remedy defects and physical or mental illnesses, whether or not the services are covered under the State Medicaid plan.

Children reportedly do not often receive the screening required under federal Medicaid law or, when a screening is done and a mental illness is detected, fail to receive the services they are entitled to receive under the law. Children must qualify to be eligible for Medicaid services, and sometimes families are unaware that they qualify. Also, some geographic areas are not served by Medicaid mental health providers, and in some states, residential treatment providers require children to be wards of the state before accepting Medicaid-eligible children.

Despite an inability to find any reported court decisions that challenge a state's refusal to provide services under the EPSDT requirements of the federal Medicaid law, the Bazelon report cites a number of cases that have had favorable results for plaintiffs and suggests that EPSDT may be a reasonable avenue to take for securing services.

## **Individuals with Disabilities Education Act (IDEA)**

The federal IDEA law is aimed at schools and seeks to ensure that "all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs" (20 U.S.C. Sec. 1400(d)(1)(A)). Children with "serious emotional disturbance who, by reason thereof, need special education and related services" are considered disabled (20 U.S.C. Sec. 1401(3)(A)). The idea of "related services" requires interpretation, and many school districts narrowly interpret IDEA's statutory language. This often results in schools refusing to provide services outside of the traditional school setting and failure to properly assess and identify children who require special education services. Such children may simply be categorized as behavior problems, which further interferes with getting mental health services.

Lawsuits under IDEA have been started to obtain a range services, but it is difficult for plaintiffs to adequately meet a two-part test. The first part requires demonstrating that the current Individual Education Plan (IEP) is not reasonably designed to enable the child to receive educational benefits. If part one is satisfied, then they must then show that the proposed residential placement is appropriate. A vast IDEA case law compendium indicates how difficult it is to win such cases. However, IDEA has reportedly been used

successfully in litigation to secure parental and family therapy outside of the school setting. (See <http://www.nami.org/youth/custody.html>.)

### **Child Welfare System**

This area is primarily concerned with Title IV-E, the Foster Care and Adoption Assistance Program, which is a federal entitlement program for children in the child welfare system and pays states a large share of the room and board costs for the out-of-home placement of children (42 U.S.C. Sec. 672). Contrary to the belief of many states that parents must give up custody of their children for this assistance, federal law allows states to receive federal reimbursement for 180 days after a child is removed from her/his home pursuant to a voluntarily placement agreement. Federal payments may continue beyond 180 days, provided there is a judicial determination that the placement is in the best interests of the child. Thus, it is not necessary for parents to relinquish custody. (See 42 U.S.C. Sec. 672(e) and <http://www.nami.org/youth/custody.html>.)

### **Proposed Solutions**

Various solutions have been proposed by the organizations identified at the beginning of and throughout this chapter. For example, the FFCMH states that Congress must enact legislation ensuring that:

1. States cannot require parents to transfer legal custody of a child with a mental health problem for the sole purpose of obtaining necessary treatment, services, or out-of-home placements or to enable the child to become eligible for Medicaid.
2. States are allowed and encouraged to use federal funds to pay for home-based and community-based services for children and their families to prevent or forestall temporary out-of-home placement when appropriate; and
3. States are required to develop community-based services to help families raise children who have mental, emotional, or behavioral disorders.

They also offer a package of federal legislative changes "designed to address the problems created for families, children, and public agencies when parents are forced to give up custody of their child in order to obtain essential mental health services and supports." (For a list of these suggestions, please refer to [http://www.ffcmh.org/New%20Site/factsheet\\_custody.htm](http://www.ffcmh.org/New%20Site/factsheet_custody.htm).)

The NAMI summary focuses on the potential usefulness of The Family Opportunity Act (FOA). The NAMI website describes the bill and the changes made to it over time, stating:

FOA is intended to end the financial devastation that families too often encounter in attempting to access quality treatment for their children with mental illnesses. As many NAMI members know firsthand, families are often tragically forced to give up custody of their children to obtain the most appropriate treatment and services for them. This legislation offers stability and recovery to children with severe and chronic disabling disorders, including early-onset mental illnesses and is a measure that will help put an end to this horrible choice that loving and caring families must make in cases where there has been no abuse or neglect.

Under the bill, states would have the option to offer Medicaid coverage to children with severe disabilities living in middle income families through a buy-in program. The Chairman's mark included a change to cover families only up to 250% of poverty not 300% as originally introduced. This means that the FOA would cover a family of four with an income of \$45,000, where at 300% it would have covered a family with an income of \$52,950. Another change included dropping the time-limited demonstration program that would allow states to extend Medicaid coverage to children with potentially severe disabilities who, without access to the health care services available through Medicaid can be reasonably expected to become severe enough to qualify them for SSI.  
<http://www.nami.org/update/20020712.html>

Finally, the Bazelon "Executive Summary" describes a number of initiatives at the federal and state levels being undertaken to resolve the problem of custody relinquishment. At the federal level, there is an official document of the Children's Bureau of the U.S. Department of Health and Human Services (PIQ-82-07), which clarifies a state child welfare agency's responsibility to be placement and care of the child, but states that "custody of the child is not a requirement" under federal law.

The Bazelon report also discusses two special Medicaid programs that can help by expanding children's access to public mental health services:

1. The "Katie Beckett" option, which "allows a state to provide Medicaid coverage for a child who would require the level of care in a hospital but could appropriately receive services elsewhere, as long as the estimated medical cost does not exceed the cost of hospital care" and
2. "A waiver of Medicaid rules that enables a state to pay for home and community-based services for a specific number and category of individuals who, without such services, would require a 'hospital level of care' paid by Medicaid."

According to the Bazelon report, state initiatives include:

1. Statutory or policy changes to child welfare systems that prohibit the agency from requiring custody relinquishment to access mental health services. Some states allow voluntary agreements between parents and the child welfare system for out-of-home placement without custody relinquishment. Title IV-E waivers also have been obtained to help with these services.
2. Several states have given courts jurisdiction to order mental health treatment or care in an effort to avert out-of-home placements.
3. Enforcing Medicaid entitlement to services.
4. Working to implement the IDEA entitlement to education-related services.
5. Developing comprehensive mental health services for children and families, i.e., Systems of Care.

6. Monitoring the use of the state's mental health block grant.
7. Federally funded systems of care for children and families.

The report notes positives and negatives related to each of these initiatives. This report is now more than two years old, and the present status of each of these initiatives is unclear.

## VI. Children's Mental Health for Native Americans: Best or Promising Practices

The information in this section is drawn largely from a presentation by Brenda Freeman, Ph.D., to the South Dakota Children's Mental Health Task Force in November 2002. Dr. Freeman presented a conceptual framework which involved four components for understanding best or promising practices: 1) barriers to services; 2) implementation of promising practices; 3) increase in Native American providers; and 4) research. The remainder of this chapter will describe each of these components as discussed in the presentation and other sources (e.g., Surgeon General's 1999 report on Mental Health).

### 1. Barriers to Services

Although there can be numerous reasons a given person or group of people do not obtain mental health treatment, three main issues are **accessibility**, **availability**, and **cultural competence** of providers and treatment protocols. Of course, each of these broad categories subsumes specific issues that are intricately interwoven in an historical context. For Native Americans, this historical context involves significant, ongoing conflict with the United States government that has bred distrust not only of governmental agencies, but an apparently generalized suspicion of Caucasians in positions of authority in many different institutions. Thus, while this section will focus on accessibility, availability, and cultural competence, relevant issues from the historical context and current circumstances will be discussed as appropriate.

#### Accessibility

The Surgeon General's report indicates that the Federal Government has responsibility for providing health care to over 500 federally recognized tribes. This is the primary purpose of the Indian Health Service (IHS), which was established in 1955 within the Department of Health and Human Services (DHHS). However, IHS clinics and hospitals are located mainly on reservations, and only 20% of Native Americans live on reservations. Thus, 80% have limited access to these services. Additionally, tribes that are recognized by a given state, but not by the federal Bureau of Indian Affairs, are ineligible for IHS funding.

According to a report made near the time of the Surgeon General's report and cited in it, about half of Native Americans had employer-based insurance coverage, 25% used Medicaid as the primary source of coverage, and 24% had no health insurance. Additionally, the IHS is undergoing significant changes due to tribes exercising options under the Indian Self-Determination Act.<sup>2</sup> Apparently this has had the result of

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<sup>t</sup> The Surgeon General's report uses the term American Indian in keeping with a 1977 resolution indicating that this is the preferred reference to people indigenous to North America.

<sup>2</sup> Brown, E. R., Ojeda, V. D., Wyn, R., & Levan, R. (2000). *Racial and Ethnic Disparities in Access to Health Insurance and Health Care*. Los Angeles: UCLA Center for Health Policy Research and The Henry J. Kaiser Family Foundation, p. 31.

decreasing federal participation in Indian health care and has diminished the ability of local providers to recover Medicaid, Medicare, and private reimbursement, which in turn reduces resources to support health care delivery. Finally, although there have been changes in policy that have enabled tribes to apply directly for substance abuse block-grant funds, it is not clear that policy changes have allowed this for mental health services.

Despite barriers to treatment related to location of facilities and coverage, there is not strong data or a sufficient amount of data to determine the extent to which Native Americans have access to treatment as a population. There are relatively few studies available, some of those that exist are not methodologically rigorous, and given the vast diversity of language and practices across the hundreds of tribes that exist across different regions of the United States, it is not clear how generalizable the findings in one area are to other places. Thus, some studies suggest that Native Americans have far less accessibility to treatment than other groups, whereas others indicate that they utilize (and therefore have access to) services in equal or greater amounts as other groups. Nevertheless, there seems to be some consistency in the finding that Native American youths are more likely to come into contact with treatment through courts or in detention centers, and that Native Americans generally are admitted at a higher rate than whites to state and local hospitals.

### **Availability**

The Surgeon General's report discusses availability of services to Native Americans strictly in terms of the number of "ethnically similar" providers. It is stated that there is likely a proportion of Native Americans who would prefer being treated by an ethnically similar person, but there are no figures regarding what this percentage might be. However, the report indicates that in 1996, only an estimated 29 psychiatrists in the U.S. were of Indian heritage, which is similar to other professions as well.

The report also discusses the limited availability of services in rural and isolated communities, which poses a problem for all residents of these areas. However, when one combines the historical context of Native Americans with limited or no facilities that specialize in working with them, they may be even less likely to utilize mental health treatment that may exist (however limited it is). On the other hand, the Surgeon General's report indicated that "several targeted studies suggest that in many cases American Indians and Alaska Natives use alternative therapies at rates that are equal to or greater than the rates for whites" (p. 93). Thus, limited treatment in the form of clinics or hospitals may, to some extent, be supplemented by traditional healing practices. These practices have the added benefit of being a product of the culture with which a person identifies.

### **Cultural Competence**

The Western Interstate Commission for Higher Education (WICHE) offers the following definition of cultural competence: cultural competence includes the attainment of knowledge, skills, and attitudes to enable administrators and practitioners within systems of care to provide effective care for diverse populations. An elaboration of this definition

as it applies to mental health practice can be found at:

[http://www.wiche.edu/MentalHealth/Cultural\\_Comp/index.htm](http://www.wiche.edu/MentalHealth/Cultural_Comp/index.htm). This website provides the full text of a report titled *Cultural Competence Standards in Managed Mental Health Care for Four Underserved/Underrepresented Racial/Ethnic Groups*.

This report also contains a chapter titled "Knowledge, Understanding, Skills, and Attitudes," which offers suggestions related to consumer populations' backgrounds, clinical issues, how to provide appropriate treatment, agency/provider role, how to communicate effectively across cultures, provide quality assessments, formulate and implement quality care and treatment plans, provide quality treatment, and use one's self and knowledge in the treatment process. It also has recommended performance indicators and recommended outcomes. See the following website for more information:

[http://www.wiche.edu/MentalHealth/Cultural\\_Comp/ccs19.htm](http://www.wiche.edu/MentalHealth/Cultural_Comp/ccs19.htm).

Dr. Freeman discussed cultural competence issues related to Native Americans and described a discontinuity between the worldviews of Native Americans and the dominant culture. Native Americans were reported to experience disorientation and distress as a result of this discontinuity, which may translate in therapy to feelings of being looked at negatively or generally being misunderstood. Since therapy is supposed to be a helpful endeavor, feeling misunderstood or negatively evaluated may facilitate even more distress.

A suggestion in this regard is to ensure that graduate programs in mental health related fields (e.g., psychology, social work, counseling) have a solid cultural competence component integrated in their curricula. Additionally, since a given culture is best understood in terms of its particular location and local practices, curricula and clinical practice should be geared toward gaining competence to treat those in one's immediate and surrounding area. However, those working in the area of cultural competence acknowledge the difficulty that is posed by the wide diversity of cultures in America. For example, the Surgeon General's report indicates that Native American cultures are extremely heterogeneous, as there are 561 federally recognized tribes, with over 200 indigenous languages spoken. "Differences between some of these languages are as distinct as those between English and Chinese" (p. 84). Thus, although some generalities may exist for a given culture that practitioners can use as heuristics, it is important for clinicians to first understand the populations with whom they will have the most direct clinical contact, then expand their knowledge base with time and experience.

## **2. Implementation of Promising Practices**

Best or promising practices with Native Americans are, in many ways, similar to recommendations of best practices for other groups. Recommendations include family and/or child-focused interventions as described in the principles of the Child and Adolescent Service System Program (CASSP), which include guidelines for implementing a system of care for children's mental health. As indicated in an earlier section, wraparound services are also considered a promising practice and are a potential component of a system of care. In both cases, the focus is on mobilizing the power of the family (or potentially the culture) to effect positive change. Such a viewpoint is consistent with many Native American beliefs about the importance of family and community in the practical and spiritual sides of life.

In this regard, Dr. Freeman discussed the need for using one's skills at cultural competence throughout the clinical process. She recommended culturally appropriate assessments and diagnoses that account for local norms and other factors (e.g., socioeconomic status). Once an appropriate diagnosis has been formulated, clinicians can then select interventions that include cultural and spiritual elements, referral for traditional healing, family or community support groups, and so forth. Unfortunately, at present, there is limited information about the extent to which a given program of treatment is generalizable to all Native American cultures. However, the active clinician can utilize knowledge of family, community members, and other clinicians to gain a better understanding of the culture and formulate appropriate treatment interventions. Additionally, clinicians can also access literature on treatment programs in different areas that have demonstrated some success and potentially alter these programs to fit the needs of their clients. Thus, although spelling out the specifics of best or promising practices with Native Americans is difficult because of limited data and research, there are a number of things clinicians can do to offer the best services they can.

### **3. Increasing the Number of Native American Providers**

Another way to potentially increase the quality of mental health treatment for Native Americans is to increase the number of Native American providers. Dr. Freeman reported that some research indicates that ethnic matching of client to clinician has an influence on the length of treatment, with a better match relating to longer treatment. However, there is not yet any data to indicate that such matching strongly improves outcomes. Nevertheless, common sense indicates that a person who is from a given culture likely has a more intricate understanding of it and therefore would be in a better position to intervene effectively with a client from the same culture.

Regarding training, Dr. Freeman reported that there are approximately 14 Native American and Alaska Native graduates per year in psychology. Factors that contribute to this low number include competition for Native American students by different programs, geographic issues and close bonds to family that limit the desire for moving to other parts of the country or region, and the difficulty of reaching Native Americans living on reservations. Additionally, Dr. Freeman reported that it is sometimes difficult to retain Native Americans in graduate programs because of a culture clash with higher education, partly for historical reasons noted above and also because of differing emphases regarding the relative importance of school, work, and family.

### **4. Research**

It has been noted in this and other reports that research focusing on Native American populations is very limited for a number of different reasons. On the one hand, the relatively small size of the Native American population, the diversity among tribes, their geographic locations, and other related factors make it difficult to gain representative research samples with generalizable results. On the other hand, research itself is expensive, time consuming, and may not occur in areas where a significant percentage of Native Americans live. These certainly are not the only barriers to conducting sound research, but are formidable in their own right.

Overcoming obstacles to research with Native Americans will probably be a long process, but one worth undertaking for a number of reasons. First, limited research inhibits treatment

effectiveness. Although clinicians in particular areas may have found successful interventions to fit their population, a growing and integrated knowledge base will assist those who have not had as much success. As evidence contributes to knowledge, decision-makers at multiple levels will have better foundations on which to direct attention and, perhaps, resources. In time, evidence-based practices will lead to improved quality of treatment and better accountability. Thus, research appropriately conducted and applied is of value not only to researchers and clinicians, but more importantly, to clients. Fortunately, clinical research has broadened its scope and methodologies in the service of gaining data that otherwise might never be gathered. Research also presents an opportunity to form working alliances between Native Americans and those who are charged with understanding and effectively attending to health and mental health needs.

## VII. Results of Key Informant Surveys: What People Think About Children's Mental Health in South Dakota

This chapter provides a summary of the results from 50 people responding to a key informant survey designed by the South Dakota Children's Mental Health Task Force.

Below is a list of major findings from the survey. The remaining sections will present demographic data and the results for the questions relating to the mental health issues that were included in the survey.

### Major Findings

- The two mental health or substance abuse problems ranked as most common were **family problems** and **alcohol abuse**. They were closely followed by mood disorders (e.g., depression, bipolar disorder), drug abuse/addiction, and attention deficit disorder.
- The services considered most available were (in order, starting with the most available): **counseling** (individual, group, family), **outpatient substance abuse, case management, crisis intervention, and state hospitals**.
- The services considered to have a critical shortage were (in order from least available): **family support, school-based mental health services, intensive in-home family therapy, wraparound services, and early identification/screening**.
- The providers ranked as least available were, in order: child psychiatrists, child psychologists, general psychiatrists, and family therapists.
- Lack of family financial resources was ranked as the number one financial barrier to children's mental health services. Lack of mental health insurance benefits was second.
- Professional shortages, stigma, and too few people to support the system of care were ranked as the most significant barriers to rural children and families with mental health needs.
- 80% of respondents indicated that family physicians or primary care providers are not prepared to meet the mental health needs of patients. Most (70%) indicated that access to mental health professionals for consultation would be helpful.
- A large majority of respondents indicated that funding provided for children's mental health in all agencies (state or community-based) was too little. There were also a number of respondents who reported not knowing whether funding is adequate or not.

Almost 80% of respondents reported that the ability of the current system to keep children out of the juvenile justice system and to support youth as they transition into adult systems of mental health care is poor.

Although more than half the respondents rated the current system as poor in enabling children to remain in their natural family as well as succeed in school, a significant percentage rated the system as adequate in this regard.

Y The majority of responses to an open-ended question regarding one recommendation to be sent to the Governor and legislature dealt with systems of care issues, funding, and school-based mental health services.

## Demographic Data and Characteristics of the Respondents

Demographic data were requested in the first eight questions, which asked about respondents' age, gender, race/ethnicity, the type of area where they live (e.g., city, town, rural), whether or not they live on a reservation, family income level, their interest in children's mental health issues, and whether or not a member of their family had received mental health services in the past 24 months in South Dakota. The results for each of these questions are presented below. Comments or explanations will be added as deemed appropriate.

### Age, Gender, and Race/Ethnicity

The age of respondents ranged from 24 to 71 (with two omissions) and averaged 45 years. Respondents were composed of 19 (38%) males and 31 (62%) females. Thirty seven respondents (74%) identified themselves as Caucasian, 12 (24%) as Native American (11 of which indicated living on a reservation), and one as Asian.

### Where Respondents Live

Location	Freq.
City (<2,500)	15
Town (2,500 - 50,000)	4
Village (<2,500)	2
Rural (farm, ranch, etc)	14

### Family Income

#### Gross Income Level Freq.

< \$20,000	5
\$20-40,000	2
\$40-60,000	.2
> \$80,000	44.9

### Respondents' Interest in Children's Mental Health

Interest/Vocation	Freq.
Youth with mental health needs.	8
Family member of youth in need.	9
Advocate.	
Mental Health Provider.	
Government Official	
Interested community member.	
Educator.	
Healthcare Provider.	
Other.	

In terms of whether respondents or one of their family members received mental health services in the past 24 months, 19 respondents (38%) reported receiving such services, while 29 (58%) indicated not receiving mental health services. Two respondents left this item blank.

## Responses to the Questionnaire

**Question 1: What are the most common mental health and substance abuse problems facing children in South Dakota?** Respondents were asked to rank order the following problems. The thirteen problems are listed below in order of their ranking.

Item	Rank
Family Problems*	1
Alcohol Abuse/Addiction*	1
Mood disorders (depression, bipolar disorder, etc) *	3
Drug Abuse/Addiction*	4
Attention Deficit Disorder*	5
Physical Abuse/Neglect*	6
Aggressive Behavior*	7
Conduct Disorders*	8
Sexual Abuse Victim	9
Suicide Threat/Attempt	10
Anxiety Disorders	11
Sexual Offender	12
Thought Disorder (psychoses)	13
Other (3 respondents only)	14

\*More than half the respondents ranked these items  
in the top 7 (top half) of their ranking

Those problems that were included in the top 7 items for at least half the respondents are marked with an asterisk. These eight items are seen as especially common problems.

**Question 2: How available are the following common services for children and families with mental health needs?** Respondents were asked to rank the top five of 22 services, where 1 is the most available and 5 is the least available of the five ranked.

**Question 3: Which of these same services are not available or have a critical shortage?** Respondents again ranked the top five of 22 services in terms of their shortage.

Item	Available Services			Unavailable Services		
	Rank	# of Re-spondents	Avg. Rank (1-5)	Rank	# of Re-spondents	Avg. Rank (1-5)
Counseling (individual, group, family)*	1	34	1.9	17	4	2.4
Outpatient Substance Abuse Services*	2	24	2.5	16	5	2.2
Case Management (Coordination of Care)*	3	23	3.0	8	13	3.2
Crisis Intervention*	3	23	3.3	11	10	2.6
State Hospital *	3	23	3.5	22	1	5.0
Psychological Assessment*	6	22	2.0	20	2	2.5
Protection and Advocacy*	7	19	3.0	14	9	2.4
Residential Treatment*	8	18	3.0	11	10	2.9
School-Based Mental Health Services <sup>++</sup>	9	17	3.1	2	20	2.9
Community-based Inpatient Hospital	10	16	2.9	8	13	3.5
Early Identification/Screening <sup>+</sup>	10	16	3.1	4	17	2.7
Crisis Shelter	12	15	2.7	14	9	2.4
Outpatient Psychiatry	12	15	3.4	7	14	2.6
Family Support <sup>+</sup>	12	15	3.5	1	21	2.4
Treatment Group Home	15	14	3.9	17	4	2.5
Vocational Counseling	16	13	3.2	19	3	2.0
Intensive In-Home Family Therapy <sup>+</sup>	17	10	3.3	3	18	2.8
Wraparound (System of Care) <sup>+</sup>	17	10	3.9	4	17	2.5
Day Treatment	19	9	3.6	6	15	3.5
Treatment Foster Care***	19	9	3.8	11	10	3.8
Independent Living Support***	21	8	3.5	10	12	3.1
Other (two used)***	22	2	NA	20	2	NA

\*At least one-third (33%) of respondents ranked this service as available (e.g., in top five)

<sup>+</sup>At least one-third (33%) of respondents ranked this service as 'unavailable' (e.g., in top five) \*

\*\* Ranked by less than 75% of respondents in both categories

Nine services (counseling, outpatient substance abuse, case management, crisis intervention, state hospital, psychological assessment, protection and advocacy, residential treatment, and school-based mental health services) were ranked as *available* by at least one-third of the respondents. Five services (school-based mental health services, early identification/screening, family support, intensive in-home family therapy, and wraparound) were ranked as *unavailable* or scarce by at least one-third of the respondents. Three services (treatment foster care, independent living support, and other - residential treatment for children 10 and under and culturally competent services) were ranked as neither common nor in need of greater emphasis or availability, as they were ranked among the top five services by one-fourth of the respondents at most.

As can be seen, school-based mental health services were rated as both available and unavailable by at least one third of respondents (17 and 20, respectively). However, there were five respondents who ranked these services as both available *and* unavailable. When compared to respondents who ranked these services as available or not available, this subset was similar on most demographic variables. However, there were three variables that appeared different: 1) they all indicated having a family member or youth with mental health needs; 2) they were more likely to have had a family member receive mental health services in the past two years; and 3) they reported lower family income relative to the other two groups. One can interpret their endorsement of school-based mental health services as both available and unavailable a number of ways, but the simplest explanation is that that they see that such services exist, but also believe there should be more of them (or perhaps that the ones that exist should be improved).

**Question 4: Often, a family physician or primary care provider is critical to the identification, referral to specialty mental health services, and on-going medication monitoring: Do you feel these providers are adequately prepared to meet this demand?**

**Question 5: IF NO: What sort of strategies might help? (Four options plus 'other' were provided as possibilities.)**

The vast majority of respondents (80%, n = 40) said **no** to this statement. The strategies they thought were most likely to help were: most (70%, n = 35) thought "access to mental health professionals for telephone and face-to-face consultation" would help. Half (50%, n = 25) thought "co-location and integration of outpatient mental health services in primary care settings" would help. A little more than one third (38%, n = 19) thought that "access to Telehealth consultation and treatment services" and/or "continuing medical education opportunities" would help. Only five of the 50 respondents checked the "other" category.

**Question 6: What do you feel are the financial barriers to children's mental health services?** Respondents were asked to rank order the four choices.

Item	Rank
Lack of family financial resources	1
Lack of health insurance mental health benefits	
Lack of health insurance	2
Services not covered by Medicaid	3
	4

Nearly half the respondents chose 'lack of family financial resources' as the number one barrier, while 72% of the respondents ranked lack of mental health insurance as the first or second barrier. Almost half (n = 15) ranked 'services not covered by Medicaid' as least important of these four factors.

Respondents were asked a question about the adequacy of funding for different services. For each question, respondents are asked whether the funding is "too little," "about right," "excessive," or "don't know."

<b>Question 1</b>				
7: Is the amount of funding provided for children's mental health services delivered in state operated facilities and community mental health agencies:				
8: Is the amount of funding provided for children's mental health services delivered in schools for children with identified emotional needs:	<u>Too little</u>	<u>About right</u>	<u>Excessive</u>	<u>Don't know</u>
	3 6 (75%)	7 (15%)	0 (0%)	5 (10%)
9: Is the amount of funding provided for mental health services for delinquent youth in state custody:	4 1 (84%)	1 (2%)	0 (0%)	7 (14%)
10: Is the amount of funding provided for mental health services for abused and neglected youth in state custody:	3 1 (63%)	9 (18%)	2 (4%)	7 (14%)
		4		
	3 9 (80%)	( 8%)	0 (0%)	6 (12%)

Among those who expressed an opinion on the above four questions (i.e., omitting the people who 'didn't know') the majority felt that funding was too little in all cases. The remainder rated the item as 'about right' with the exception of two respondents who felt that there is an excess of funding for mental health services for delinquent youth in state custody.

**Question 11: Of the providers who deliver mental health services to children and families, which do you feel are the least available and/or have significant shortages?** Respondents were asked to rank order the providers.

Item	Rank
Child Psychiatrist*	1
Child Psychologist*	2
General Psychiatrist*	3
Family Therapist *	4
Psychologist	5
Mental Health Counselor	6
Psychiatric Nurse	7
Clinical Social Worker	8
Other (5 responses)	9

\*At least one third of the respondents ranked the item fourth or higher

Four categories of mental health workers were perceived as being least available and/or in significant shortage. These were: child psychiatrists, child psychologists, general psychiatrists, and family therapists.

**Question 12: How well do you feel the current system of services for children and families with mental health needs does at achieving the following outcomes?**

	Poor	Adequate	Excellent
Enabling children to remain in their natural family.	27 (56%)	19 (40%)	2 (4%)
Enabling children to succeed in school.	31 (65%)	17 (35%)	0 (0%)
Keeping children out of the juvenile justice system.	38 (79%)	10 (21%)	0 (0%)
Supporting youth as they transition into adult systems of mental health care.	35 (78%)	9 (20%)	1 (2%)

The majority of respondents indicated that outcomes were poor in all cases. Of these four issues, "enabling children to remain with their family" was rated most favorably on average.

**Question 13: Of the issues that are listed below, rank order their significance as barriers to rural children and their families with mental health needs? (1 = most significant)**

Item	Rank
Professional shortages*	1
Attitudes toward seeking care (stigma	
Geographic population density (too few people to support system of care)*	
Cost of service deliver-	
Health insurance benefits*	5
Transportation	
Recruitment/retention	7
Other	

\* At least one third of the respondents ranked the item third or higher

Most of the issues listed above were perceived as significant barriers by at least one third of the respondents. Of the issues listed, only transportation and recruitment/retention were seen as relatively less significant barriers. There were four 'other' responses, two of which discussed funding problems, one indicated that all the above were significant, and the other indicated that Indian Health Services was solely the place for treatment.

**Question 14: If you could choose one (only one) recommendation for this task force to forward to the Legislature and Governor, what would it be?**

Recommendations are listed below verbatim from written comments (except minor grammatical changes). The recommendations are being grouped based on common themes, but it is recognized that a given issue in one group may relate to issues in other groups. Thus, the reader should consider these groups as somewhat "fluid." The groups are listed in no particular order.

**System of Care**

- Develop integrated system of care with SED by combining fiscal and efforts of staff from all appropriate state agencies so children and families truly experience "no wrong door" when in need of services.
- Clearly conceptualize and adequately fund a meaningful system of care for children across the state.
- Integration of services - removal of organizational and structural barriers.
- Develop a system of care that is community based, we are too heavily dependent on residential care. Develop mental health programming that all SED youth can be served IN STATE!
- We could use more of a wrap around system of care. It is critically beneficial.
- Need to have a system of care for children who do not qualify as **SED** or chronically persistent mentally ill.
- Improve service delivery - INTENSIVE community services.
- Better coordination between all agencies that children may be involved in.
- Create transitional living centers for adolescents throughout the state.
- Provide an option for residential treatment based on mental health professional recommendation.
- Family support similar to the D.D. system.
- Availability of residential treatment or intense-in-home treatment that could be used without significant financial burden to family without making it totally out of range. Otherwise parental rights are relinquished.

**Relinquishment of Custody**

- Enable the system of care to allow families access to higher levels of care without having to relinquish custody of their child.
- Resolve issue of parents giving up custody in order to receive needed services.
- Allow parents to maintain child custody while receiving state mental health services.
- Helping children to remain in their natural family.
- Provide funding and identify the pathway for families to address children's mental health needs without having to relinquish custody to the state - DOC/DSS. State agencies can become a dumping ground for children and the only way to get services.

## School-Based Mental Health Services

- School based mental health services statewide (this is beyond just having access to a school counselor). Ideally this would be a coordinated effort between school counselors and community MH providers.
- Take seriously the need for professional counselors in the schools. We do need a mandate.
- Mandatory school counseling services as a first line intervention process.
- Support reinstating counselor mandates for schools.
- Hire school social workers. Hire school counselors.
- Add school counselors to all schools (elementary to high school). Students need to feel they have an advocate.
- Try to create more availability to children and their family's services without hearing that the school board system has to be involved (Why are they having to be involved in every decision?)

## Funding

- Increase funding to provide mental health services to the children.
- More money for children's health in all areas.
- Provide more funding.
- Support recommendations of task force and provide adequate funding streams to achieve success.
- Close examination of funding streams.
- Increased funding generally and specifically for early identification and treatment.
- Look at changing Medicaid SED funding levels for non-CMHCs that provide services. Current system requires to staff but funds low level + excludes case management. Problems: 1) limits access; 2) reduces wrap around (only funds CMHC).
- Medicaid benefits to tribal services.
- Medicaid reimbursement. Third party billing.
- That Medicare be made available to tribes on reservations to help in cost to help in giving care to our people.

## Early Identification/Screening

- Early identification and intervention - coordinate MH services w/DSS child protection services with the intervention occurring PRIOR to the physical abuse.
- Address early childhood placement in foster care system to improve/extend placements to provide supportive environment so children are protected and learn to attach to others. Evaluate the standards related to when children are permanently removed.
- More money for early intervention with children from birth to age three.

## Cultural Competence

- Cultural competence - not only race but family culture also. Very important in helping children to help themselves and also their families.
- Seek more collaboration between the state and the tribe. Don't push it back on the government as a treaty obligation. Seek avenues for third party billing.

## Public Education

- Massive public education that mental illnesses are no different than any other illness. There is treatment available. It does not mean you are a bad family or have a bad child if your child has mental illness problems.
- That more exposed to mental health needs and a way for families to find the resources they can get.

## Other

- Address the issue of why children and youth/families services are not a priority when children are the future.
- Too early in the process to say...
- LPC need to be able to provide T- 19 services.

## VIII. Task Force Recommendations

This chapter lists several recommendations that were generated at Task Force meetings facilitated by WICHE using a consensus-building method. The recommendations were generated through multiple data points. These included open dialogue and input from Task Force members and interested citizens who attended the meetings and offered public comment. Public comment came in the form of testimonials and responses to a Key Informant Survey. Best practices for Native Americans were reviewed. Additionally, prevalence and utilization data sharpened the focus of and provided a sound basis for the recommendations. In this regard, brief rationales and references to relevant areas of this report will be included for each recommendation.

### Recommendations

**1. The Director of the Division of Mental Health shall work through the Mental Health Planning and Coordination Advisory Council to develop an action plan detailing options for parents/families of children with serious emotional disturbance (SED) to obtain public services without relinquishing child custody. This action plan shall be delivered to the Governor and Legislature by December 2003.**

Testimonials and comments from participants in the Task Force meetings described a strong desire to see action taken to address the very problematic issue of relinquishing custody to obtain services. For a description of the problem and related issues, see Chapter V (p. 27). Key Informant Survey data also speak to this problem (see p. 46).

**2. Children and adolescents in the State of South Dakota shall be screened for social emotional development to promote early identification and intervention needs. This screening shall be integrated into existing services such as public health, school, and day care settings.**

Early identification and screening for children is considered a standard aspect of systems of care for children (p. 17). It was ranked in the top five of those services considered to have a critical shortage (pp. 38, 42) and generated significant comment in the Key Informant Survey (p. 47).

**3. The first step in seeking care is the knowledge regarding both the need for help and where to go for help. The Department of Human Services in cooperation with other public and private entities, shall initiate a public education campaign to increase public awareness of family, child and adolescent mental health issues and local resources for care.**

Public education was another topic that was discussed at some length during Task Force meetings (refer to Minutes) and was also offered as one of the recommendations to be sent to the state government by Key Informants (p. 48).

**4. Local and State interagency collaboration is required to developing an effective system of care for children and families with mental health care needs. Interagency collaboration assures children and families progress to appropriate services on a continuum of care. Local areas need flexibility in building a system of care that works for their communities. State agencies shall coordinate to support the development of local systems of care through policies, regulations and funding mechanisms.**

For a full description systems of care, see Chapter IV on Best Practices (p. 17). Problems with the current system of care were viewed as a significant barrier to treatment, ranked in the top five areas of critical shortage (p. 42), and generated the most comments in an open-ended question on the Key Informant Survey (p. 46).

**5. The Legislature should explore means to enhance the availability of professionals trained to meet the mental health needs of children and adolescents, including statutory changes and training support of both new and existing professionals.**

According to results of the Key Informant Survey (pp. 38, 41-42) and data from the needs assessment (pp. 12, 14), a large percentage of children do not receive mental health or substance abuse services. A significant reason is a shortage of providers, especially for rural children and their families (pp. 38, 44-45).

**6. Significant gaps in a continuum of services exist because of multiple factors. It is recommended that the Department of Human Services work with other State agencies to enhance funding for all services for children and families with behavioral health needs.**

Less than half of children and adolescents needing public mental health services are receiving them from Community Mental Health Centers funded through State contracts or Medicaid (see Chapter III, p. 12). For a brief description of the Medicaid system in South Dakota, see p. 9. Medicaid options within a system of care are discussed on pages 25-26. As Medicaid relates to relinquishment of custody to obtain services, see pages 28-32. Finally, there was significant commentary in the Key Informant Survey regarding funding for services, of which Medicaid was a part (p. 47).

**7. The Department of Human Services and all mental health programs and staff throughout the state shall be knowledgeable and responsive to the diverse cultural backgrounds represented in the state. This recommendation is not separate but cuts across the implementation of all preceding recommendations.**

Meeting the needs of diverse groups requires knowledge of their backgrounds and competence in effective interventions. These issues were raised by Task Force members and the public during meetings, as well as on the Key Informant Survey (p. 48). Please see Chapter VI (p. 33) for a description of relevant issues in this regard.

## IX. Task Force Members

### South Dakota Members

<b>Name</b>	<b>Representing</b>	<b>Contact Information</b>
Rep. Matthew Michels	House of Representatives	1213 Walnut Street Yankton, SD 57078 665-8700
Sen. John McIntyre	Senate	3204 S. Jefferson Ave. Sioux Falls, SD 57105-5321 338-9959
Janet Ricketts	Dept. Education and Cultural Affairs	700 Governors Drive Pierre, SD 57501 773-4437
Sharon Sonnenschein	Dept. Social Services	700 Governors Drive Pierre, SD 57501 773-3165
Dallas Johnson	Unified Judicial System	%500 East Capitol Pierre, SD 57501 773-3474
Kim Malsam-Rysdon	Dept. of Human Services	Division of Mental Health c/o 500 East Capitol Pierre, SD 57501 773-5991
Cory Nelson	Dept. of Human Services	Human Services Center PO Box 76 Yankton, SD 57078-0076 668-3102
Doug Herrmann	Dept. of Corrections	Custer Youth Corrections Center RR1, Box 98 Custer, SD 57730-9647 673-2521
Judy Hines	Family of child	200 N. Maple Avenue Brandon, SD 57005 582-8475
Nancy Kremin	Family of child	3006 N. Fiero Place Sioux Falls, SD 57104 331-6417
Cindy Klein	Family of child	1906 Barbara Avenue Sturgis, SD 57785 720-6564
Jane York	Family of child	152 Lewis and Clark Trail Yankton, SD 57078 665-3022

Duane Majeres	Provider rep- MH center	Community Counseling Services 1552 Dakota, South Huron, SD 57350 352-8596
Johanna Simpson	Provider rep- professional	1517 Tahoe Trail Sioux Falls, SD 57110 334-2689
Thomas Otten	Provider rep- residential treatment/inpatient	Avera McKennan Behavioral Health 800 E. 21 <sup>st</sup> St. Sioux Falls, SD 57105 322-4336
Jim Ruhe	Provider rep.- professional (MH Center)	Behavior Management Systems 350 Elk Street Rapid City, SD 57701-7388 343-7262
Karen Wiemers	Provider rep.- professional (non MH Center)	Hope Psychological Services 103 E. Lawler Ave. Chamberlain, SD 57325 734-6347
Robert Kean	Advocacy organization	South Dakota Advocacy Services 221 S. Central Pierre, SD 57501 224-8294
Ethleen Iron Cloud Two Dogs	Provider/Advocacy organization	Nagi Kicopi (Calling the Spirit Back) PO Box 325 Porcupine, SD 57772 867-2883
Mel Harrington	Family or provider rep.	Lutheran Social Services 705 E. 41 <sup>st</sup> St. Sioux Falls, SD 57105 357-0100

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